

## ORIGINAL ARTICLE

# One-Year Outcomes in Caregivers of Critically Ill Patients

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## ABSTRACT

**BACKGROUND**

Few resources are available to support caregivers of patients who have survived critical illness; consequently, the caregivers' own health may suffer. We studied caregiver and patient characteristics to determine which characteristics were associated with caregivers' health outcomes during the first year after patient discharge from an intensive care unit (ICU).

**METHODS**

We prospectively enrolled 280 caregivers of patients who had received 7 or more days of mechanical ventilation in an ICU. Using hospital data and self-administered questionnaires, we collected information on caregiver and patient characteristics, including caregiver depressive symptoms, psychological well-being, health-related quality of life, sense of control over life, and effect of providing care on other activities. Assessments occurred 7 days and 3, 6, and 12 months after ICU discharge.

**RESULTS**

The caregivers' mean age was 53 years, 70% were women, and 61% were caring for a spouse. A large percentage of caregivers (67% initially and 43% at 1 year) reported high levels of depressive symptoms. Depressive symptoms decreased at least partially with time in 84% of the caregivers but did not in 16%. Variables that were significantly associated with worse mental health outcomes in caregivers were younger age, greater effect of patient care on other activities, less social support, less sense of control over life, and less personal growth. No patient variables were consistently associated with caregiver outcomes over time.

**CONCLUSIONS**

In this study, most caregivers of critically ill patients reported high levels of depressive symptoms, which commonly persisted up to 1 year and did not decrease in some caregivers. (Funded by the Canadian Institutes of Health Research and others; ClinicalTrials.gov number, NCT00896220.)

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UNPAID CAREGIVERS (TYPICALLY FAMILY or close friends) are essential to the sustainability of North American health care systems, because their unpaid labor annually accounts for \$27 billion in Canada and \$642 billion in the United States.<sup>1,2</sup> More than half the patients who have received prolonged mechanical ventilation during a stay in the intensive care unit (ICU) and have survived to discharge continue to require assistance from a caregiver 1 year after ICU discharge.<sup>3</sup> Although caregiver assistance can be beneficial for patients, such care may have negative consequences for caregivers, including poor health-related quality of life,<sup>4</sup> emotional distress,<sup>4,8</sup> a subjective sense of burden,<sup>9</sup> and symptoms of post-traumatic stress disorder.<sup>10</sup> Preliminary reports suggest that caregivers have worse health outcomes when providing higher levels of care,<sup>4</sup> undergoing lifestyle disruptions due to caregiving,<sup>4,5</sup> or caring for patients with higher levels of physical and psychological impairment.<sup>11</sup> However, previous findings are inconsistent owing to small sample sizes, short-term follow-up, and lack of simultaneous consideration of both patient and caregiver contributions to caregiver health outcomes. Ultimately, poor caregiver outcomes may compromise patients' rehabilitation potential<sup>12</sup> and the sustainability of home care,<sup>13</sup> as observed in patients with stroke and elderly persons, respectively. Identification of risk factors for caregiver distress is an important first step to minimize suffering and allow ICU survivor-caregiver dyads to regain active and fulfilling lives.

The RECOVER (Rehabilitation and Recovery in Patients after Critical Illness and Their Family Caregivers) program was based on previous research on outcomes in patients with the acute respiratory distress syndrome and their caregivers.<sup>4,14-16</sup> The program was extended to a multicenter, prospective, parallel cohort of all patients who had received mechanical ventilation for a minimum of 7 days in the ICU and had survived to discharge and their caregivers. Our objectives for the caregiver part of the study were to describe health outcomes in caregivers, identify subgroups of caregivers with distinct health trajectories, and identify variables associated with poor caregiver outcomes. Our a priori hypotheses were that more severe patient disability at 7 days after ICU discharge and the follow-up year and, in caregivers, higher levels of care provided, more restriction on personal activities, and less social

support and mastery (sense of control) would be associated with worse caregiver mental and physical health.

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## METHODS

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### PARTICIPANTS

From February 2007 until March 2014, we identified caregivers of patients who had received at least 7 days of mechanical ventilation and who were discharged alive from ICUs in 1 of 10 university-affiliated hospitals in Toronto, Hamilton, Ottawa, Montreal, Sherbrooke, and Vancouver, Canada. We defined caregivers as family members or friends who were primarily responsible for providing or coordinating care after hospital discharge, without financial compensation, to patients who were discharged alive from the ICU. For each ICU survivor, we recruited one caregiver who was at least 18 years of age and able to read and speak English or French. If a patient died during the follow-up period, caregivers were removed from further follow-up but their existing data were included in the analyses. The research ethics board at each participating center approved the study protocol, and all participants provided written informed consent.

### QUESTIONNAIRES

#### *Data Collection*

Data collection was informed by Pearlin's Stress Process Model of family caregiving.<sup>17</sup> This comprehensive model posits that caregiver health outcomes, including mental and physical health, are influenced by specific aspects of the caregiving situation such as contextual factors, primary and secondary stressors, and psychosocial resources (Fig. S1 in the Supplementary Appendix, available with the full text of this article at NEJM.org). All data were collected with the use of self-administered validated questionnaires. A total of four assessments were performed, at 7 days (baseline) and at 3, 6, and 12 months after patient discharge from an ICU.

#### *Caregiver Outcomes*

Data on caregiver outcomes were collected at all four assessments. We assessed depressive symptoms (according to the score on the 20-item Center for Epidemiologic Studies Depression [CES-D] scale<sup>18</sup>), psychological well-being (according to the score on the 10-item Positive Affect Scale of the Positive and Negative Affect Schedule [PANAS]<sup>19,20</sup>),

and physical and mental health (according to the scores on the Physical Component Summary [PCS] and Mental Component Summary [MCS] of the Medical Outcomes Study 36-Item Short-Form Health Survey [SF-36])<sup>21</sup>. Scores on the CES-D scale range from 0 to 60, with scores of less than 16 considered to be “normal,” scores of 16 to 21 suggesting a risk of clinical depression,<sup>6,18</sup> and scores of more than 21 suggesting a major depressive episode (92% sensitivity and 87% specificity<sup>22</sup>). Caregivers with moderate-to-severe depressive symptoms during follow-up were offered access to mental health professionals (see the Supplementary Appendix). Scores on the PANAS Positive Affect Scale range from 10 to 50, with higher scores indicating more psychological well-being.<sup>19,20</sup> PCS and MCS scores range from 0 to 100, with higher scores indicating better physical health and mental health, respectively.<sup>21</sup>

#### *Caregiver Independent Variables*

At baseline, we collected data on caregiver demographic characteristics, including age, sex, relationship to the patient, marital status, educational level, income level, and previous experience with caregiving. Caregivers completed the following scales at baseline and at 3, 6, and 12 months: the 20-item Medical Outcomes Study Social Support Survey,<sup>23</sup> Pearlin and Schooler's 7-item Mastery Scale,<sup>24</sup> the 17-item Caregiver Assistance Scale,<sup>25,26</sup> the 14-item Caregiving Impact Scale,<sup>25,26</sup> and the 4-item Personal Gain Scale.<sup>17</sup> Scores on the Social Support Survey range from 0 to 100, with higher scores indicating more perceived support. Scores on the Mastery Scale range from 7 to 28, with higher scores indicating a greater sense of control over life. Scores on the Caregiver Assistance Scale range from 0 to 102, with higher scores indicating that caregivers provide more assistance to patients with daily activities and medical care. Scores on the Caregiving Impact Scale range from 0 to 84, with higher scores indicating that provision of care interferes more with caregivers' abilities to maintain participation in valued activities. Scores on the Personal Gain Scale range from 4 to 16, with higher scores indicating greater discovery of inner strengths as a result of providing care.

#### *Patient Independent Variables*

The RECOVER program patient data and outcomes are described in detail elsewhere.<sup>27,28</sup> In brief,

patient data included age, sex, severity of illness (as assessed with the Acute Physiology and Chronic Health Evaluation [APACHE] II<sup>29</sup> and Multiple Organ Dysfunction Score<sup>30</sup>), coexisting conditions (as assessed with the Charlson<sup>31</sup> and Elixhauser<sup>32</sup> scales), ICU length of stay, self-care assistance required (as assessed with the Functional Independence Measure [FIM]<sup>33</sup>), walking ability (as assessed with the 6-minute walk test<sup>34</sup>), depressive symptoms (as assessed with the Beck Depression Inventory-II [BDI-II]<sup>35</sup>), post-traumatic stress symptoms (as assessed with the Impact of Event Scale [IES]<sup>36</sup>), and physical and mental health (as assessed with the PCS and MCS of the SF-36, described above<sup>21</sup>). Scores on the FIM motor subscale range from 13 to 91, with higher scores indicating more independence in everyday activities; scores on the cognitive subscale range from 5 to 35, with higher scores indicating better social functioning and communication. The 6-minute walk test assesses independence in walking, as indicated by the number of meters walked in 6 minutes. BDI-II scores range from 0 to 63, with higher scores indicating more depressive symptoms. IES scores range from 0 to 88, with higher scores indicating more symptoms of post-traumatic stress. Scores on the 6-minute walk test and FIM were assessed at baseline and at 3, 6, and 12 months after ICU discharge, and depressive symptoms, post-traumatic stress, and physical and mental health were assessed at 3, 6, and 12 months after ICU discharge.

#### **STATISTICAL ANALYSIS**

The sample size for the RECOVER studies was based on a requirement of 300 ICU survivors continuing in the study to 12 months<sup>27</sup>; we expected two thirds of these patients to have a caregiver and provide sufficient observations for longitudinal and latent growth curve modeling. Descriptive statistics (presented as means and standard deviations or counts and percentages) were calculated for caregiver and patient demographic characteristics. We determined the percentage of caregivers at risk for clinical depression and a major depressive episode using CES-D scores over 15 and over 21, respectively, at each assessment time point.

Using the CES-D score as a representative caregiver mental health outcome, we fit latent class linear mixed models<sup>37,38</sup> to data collected serially during the first year after ICU discharge

to identify groups of caregivers whose outcomes followed similar underlying trajectories over time (for details, see the Supplementary Appendix). To identify factors associated with caregiver outcomes (i.e., depressive symptoms, psychological well-being, and physical and mental health), we used mixed-effects modeling for longitudinal data, handling heterogeneity among participants with random intercepts and repeated within-participant observations with an autoregressive correlation structure on the residuals.<sup>39</sup> The prespecified main model included 25 fixed effects parameters. To enhance comparisons among continuous predictors, their estimated coefficients and 95% confidence intervals are presented as the change in outcome per standard deviation in predictor. Analyses followed the Pearlman model to examine the effect of contextual factors (caregiver and patient demographic characteristics and patient coexisting conditions), primary stressors (the amount of assistance that the caregiver provided to the patient as well as patient walking ability, independence in everyday activities, social functioning and communication, depressive symptoms, post-traumatic stress symptoms, and mental and physical health), secondary stressors (effect of caregiving on lifestyle and personal growth), and psychosocial resources (caregiver mastery and social support) on caregiver outcomes (Fig. S1 in the Supplementary Appendix).

The multivariate imputation by chained-equations algorithm in R software<sup>40</sup> was used for multiple imputation of missing predictors; the missing-data model used all baseline variables and only values of the missing longitudinal variable that were available at other times as predictors (see the Supplementary Appendix). Because we were not able to collect all patient data at the 7-day assessment, we computed separate models for situations in which patient data were available at all follow-up times and in which patient data were available only at 3, 6, and 12 months after ICU discharge.

To facilitate interpretation of multivariable models, we estimated the 6-month mean of each outcome variable for caregivers with combinations of low (25th percentile) and high (75th percentile) scores on three independent variables (mastery, effect of caregiving on other activities, and social support) with the largest standardized estimates from the multivariable models.<sup>41</sup> To compute the estimates, other variables in-

cluded in the models were set at their means or reference levels.

## RESULTS

### PARTICIPANT CHARACTERISTICS

Participant recruitment and follow-up are summarized in Figure S2 in the Supplementary Appendix. Of 330 caregivers approached, 280 were enrolled. Of the enrolled caregivers, 238 (85%) completed at least one assessment, 196 (70%) completed at least three assessments, and 154 (55%) completed all four assessments. The mean ( $\pm$ SD) age of the caregivers was 53.2 $\pm$ 13.4 years, 70% were women, and 61% were caring for their spouse (Table 1). The mean age of the corresponding 238 patients was 55.6 $\pm$ 16.2 years, and 60% were men; patients had spent a mean of 25.0 $\pm$ 16.9 days in the ICU (Table S2 in the Supplementary Appendix). The characteristics of patients with a caregiver were similar to those of patients without a caregiver (Table S2 in the Supplementary Appendix). In addition, patients progressively improved in their functional ability during the 1-year follow-up period but, on average, reached less than 75% of their walking potential as determined by the 6-minute walk test (Fig. S3 in the Supplementary Appendix).

### CAREGIVER OUTCOMES

The percentage of caregivers with a CES-D score of 16 or more was 67% at 7 days, 49% at 3 months, 43% at 6 months, and 43% at 12 months (Fig. 1A), findings that suggest that many caregivers were at risk for clinical depression. Similar patterns were observed with respect to psychological well-being (score on the PANAS Positive Affect Scale) and mental health (MCS score), whereas physical health (PCS) scores were above average and stable over time. Using latent class linear mixed models, we identified two groups of caregivers: those whose depressive symptoms decreased over time (84%) and those whose depressive symptoms persisted at a high level for up to 1 year (16%) (Fig. 1B). There were no significant differences between these groups in caregiver demographic characteristics, but significant differences were observed in assessments of independent and outcome variables at baseline (Table 1). There were no significant differences between these caregiver groups with respect to patient characteristics (Table S2 in the Supplementary Appendix).

**Table 1. Characteristics of the Caregivers at Baseline.\***

Characteristic	All Caregivers (N=238)	Caregivers Whose Depressive Symptoms Decreased over Time (N=199)	Caregivers Whose Depressive Symptoms Remained High (N=39)	P Value†
Age — yr	53.2±13.4	53.4±13.8	52.3±11.2	0.54
Female sex — no. (%)	166 (70)	137 (69)	29 (74)	0.57
Caring for spouse — no. (%)	144 (61)	119 (60)	25 (64)	1.00
Married or in common-law relationship — no./total no. (%)	195/234 (83)	164/196 (84)	31/38 (82)	0.77
Completed postsecondary education or more — no./total no. (%)	121/236 (51)	102/198 (52)	19/38 (50)	0.22
Annual income >\$70,000 in Canadian \$ — no. (%)	90 (38)	78 (39)	12 (31)	0.59
Living with care recipient full time — no./total no. (%)	164/237 (69)	139/198 (70)	25/39 (64)	0.11
Employment status — no. (%)				0.25
Working for pay	141 (59)	115 (58)	26 (67)	
Retired, volunteer, unemployed, or receiving disability	69 (29)	62 (31)	7 (18)	
Homemaker or caregiving as primary daily activity	28 (12)	22 (11)	6 (15)	
Parent of children <16 yr of age — no. (%)	25 (11)	21 (11)	4 (10)	0.40
<b>Assessments</b>				
Score on PANAS Positive Affect Scale‡	31.1±8.8	31.6±8.6	28.9±9.5	0.10
Score on SF-36 Mental Component Summary§	33.4±13.9	35.5±13.7	22.5±9.6	<0.001
Score on SF-36 Physical Component Summary¶	51.8±9.2	52.7±9.0	47.6±9.2	0.003
Score on Mastery Scale	19.9±3.8	20.4±3.7	17.4±3.7	<0.001
Score on Caregiver Assistance Scale**	41.7±23.0	40.0±23.0	50.4±21.2	0.006
Score on MOS Social Support Survey††	70.1±23.6	73.2±21.8	53.9±26.7	<0.001
Score on Caregiving Impact Scale‡‡	37.4±22.3	34.4±21.8	52.6±18.5	<0.001

\* Plus-minus values are means ±SD. Baseline was 7 days after patient discharge from an intensive care unit (ICU). The two groups of caregivers categorized according to the pattern of depressive symptoms during the first year after patient discharge from the ICU were identified with the use of latent class linear mixed models (see the Methods section of the Supplementary Appendix). Depressive symptoms were assessed according to the score on the Center for Epidemiologic Studies Depression (CES-D) scale; scores range from 0 to 60, with higher scores indicating more symptoms of depression. To convert Canadian dollars to U.S. dollars, multiply by 0.78.

† P values are for the comparison between patients whose depressive symptoms decreased over time and patients whose depressive symptoms remained high. The values should be interpreted with caution because the two groups were not directly observed but were inferred from the pattern of CES-D scores over time. Values were calculated with the use of Fisher's exact test for categorical variables and the Wilcoxon rank-sum test for continuous variables.

‡ Scores on the Positive Affect Scale of the Positive and Negative Affect Schedule (PANAS) range from 10 to 50, with higher scores indicating more psychological well-being.

§ Scores on the Mental Component Summary of the Medical Outcomes Study 36-Item Short-Form Health Survey (SF-36) range from 0 to 100, with higher scores indicating better mental health.

¶ Scores on the Physical Component Summary of the SF-36 range from 0 to 100, with higher scores indicating better physical health.

|| Scores on the Mastery Scale range from 7 to 28, with higher scores indicating a greater sense of control over life.

\*\* Scores on the Caregiver Assistance Scale range from 0 to 102, with higher scores indicating that caregivers provide more assistance to patients with daily activities and medical care.

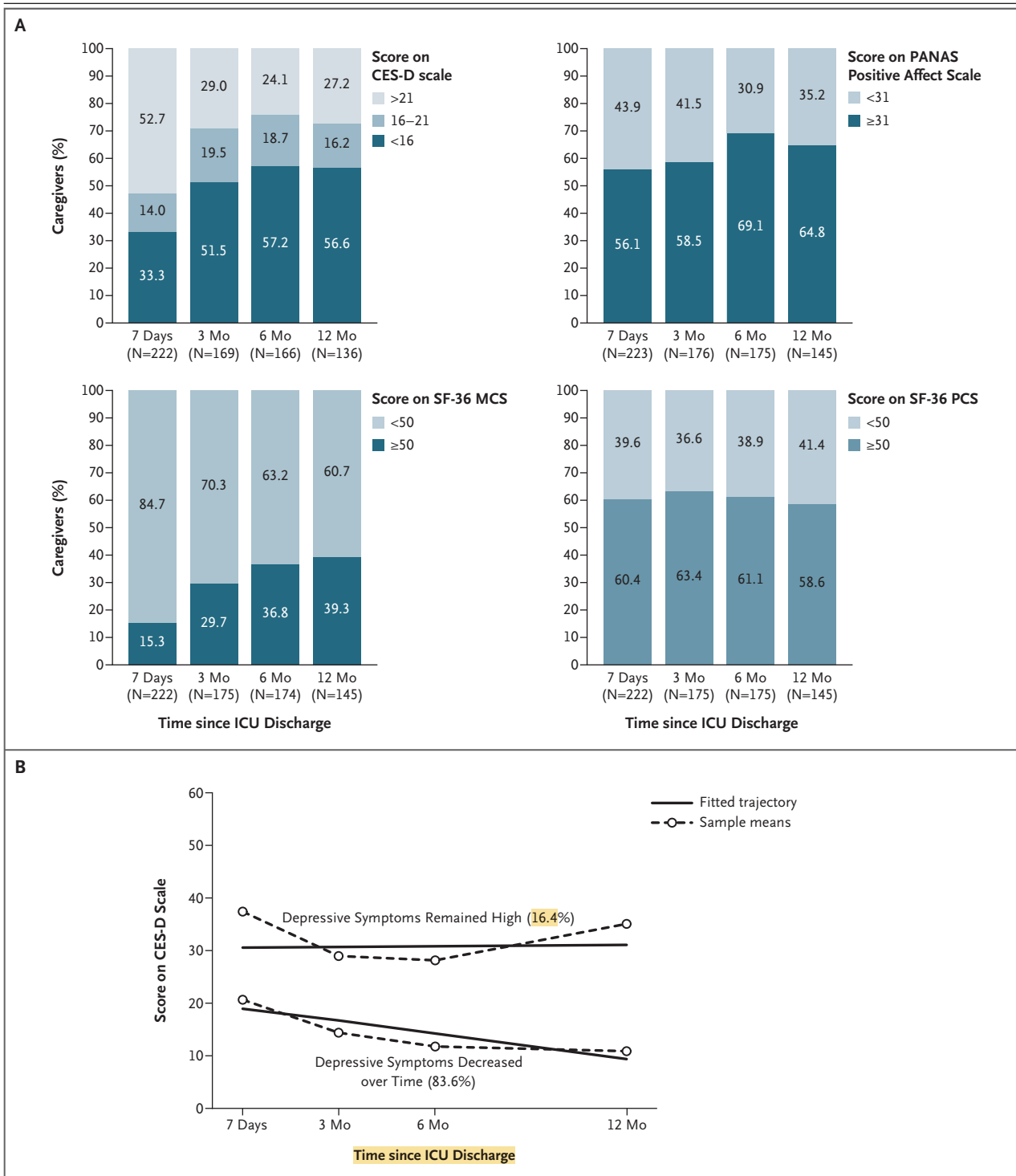
†† Scores on the Medical Outcomes Study (MOS) Social Support Survey range from 0 to 100, with higher scores indicating more perceived support.

‡‡ Scores on the Caregiving Impact Scale range from 0 to 84, with higher scores indicating that provision of care interferes more with caregivers' abilities to maintain participation in valued activities.

**FACTORS ASSOCIATED WITH CAREGIVER OUTCOMES**

Multivariable mixed-effects models were not able to identify any patient characteristics that were significantly associated with caregiver outcomes during the 1-year follow-up period (Table 2, and

Table S3 in the Supplementary Appendix). In caregivers, more depressive symptoms, less psychological well-being, and worse mental health were significantly associated with younger caregiver age, greater effect of patient care on other



activities, less social support, less mastery (sense of control over life), and less personal growth (Table 2, and Table S3 in the Supplementary Appendix). Lower physical health scores in caregivers were significantly associated with providing more assistance, having less mastery (sense of control), being older, and having an annual family income below \$50,000 in Canadian dollars (approximately \$39,000 in U.S. dollars). Caregiver mastery (sense of control), effect of caregiving on other activities, and social support had the largest relationships with the outcomes.

**Figure 1 (facing page). Caregiver Outcomes during the First Year after Patient Discharge from an Intensive Care Unit (ICU).**

Panel A, top left, shows the distribution of scores on the Center for Epidemiologic Studies Depression (CES-D) scale. CES-D scores of less than 16 are considered to be “normal,” scores of 16 to 21 suggest a risk of clinical depression, and scores over 21 suggest a major depressive episode. Also shown in Panel A are the percentage of caregivers scoring below or at or above the population norms for the Positive Affect Scale of the Positive and Negative Affective Schedule (PANAS; score of 31), the Mental Component Summary (MCS) of the Medical Outcomes Study 36-Item Short-Form Health Survey (SF-36) (score of 50), and the Physical Component Summary (PCS) of the SF-36 (score of 50). Scores on the PANAS Positive Affect Scale range from 10 to 50, with higher scores indicating more psychological well-being. MCS and PCS scores range from 0 to 100, with higher scores indicating better mental health and physical health, respectively. Panel B shows two groups of caregivers characterized by their pattern of depressive symptoms during the first year after ICU discharge. Fitted trajectories are the predicted values from the fitted latent class linear mixed models by which two groups of caregivers were identified. The sample means are the means of the values in each latent class at each time point.

Caregivers who reported low mastery (sense of control), a large effect of caregiving on other activities, and low social support also reported worse scores for depressive symptoms, psychological well-being, and mental health than those who scored well on these variables (Fig. S5 in the Supplementary Appendix). Only mastery scores influenced caregiver physical health, with lower scores associated with worse physical health. There was no evidence of collinearity, with all variance inflation factors (which measure the relative increase in the variance of the parameter estimate resulting from the correlation of the corresponding predictor with other predictors) being 3.4 or smaller.

## DISCUSSION

In this longitudinal study, caregivers of patients who had received mechanical ventilation in the ICU for at least 7 days were at risk for poor mental health outcomes, whereas their physical health was similar to population norms. Caregiver outcomes did not appear to be related to patient demographic and clinical characteristics or to changes in patient functional and psychological outcomes over time. We identified caregiver

characteristics that may help identify caregivers at risk for poor outcomes. Although we did not know caregivers' mental health status before patients' critical illness events, depressive symptoms did decrease over time for most caregivers except within a subgroup who had more severe symptoms than the rest of the sample at all time points.

Our findings suggest that a substantial percentage of caregivers may be at risk for clinical depression. Previous research has shown that the CES-D scale is a good screening tool for clinical depression.<sup>22</sup> In our sample, 43% of caregivers had a score of more than 15 on the CES-D scale at 12 months after the patients for whom they were caring were discharged from the ICU, suggesting persistent symptoms of clinical depression. This rate is substantially higher than the rate in the Canadian adult population (12%)<sup>42</sup> and is also higher than the rate observed in a large sample of caregivers of persons with dementia (32%).<sup>43</sup> In previous studies that used a CES-D score of 15 as a cutoff, 34% and 23% of caregivers of patients who had been mechanically ventilated for a minimum of 48 hours in the ICU had persistent symptoms of clinical depression at 2 months and 12 months, respectively.<sup>6,44</sup> In a small pilot study that involved caregivers of ICU patients who had received at least 4 days of mechanical ventilation and survived to discharge and that used a shortened version of the CES-D scale, the percentage of caregivers who were at risk for clinical depression was 90% while the patients were in the ICU and 61% at 2 months after the patients were discharged.<sup>45</sup> Taken together, these studies suggest that caregivers of patients who receive mechanical ventilation in the ICU and are discharged alive from the hospital are at higher risk for clinical depression than are persons in the general population and than are caregivers of persons with chronic progressive illnesses such as Alzheimer's disease.

Using two longitudinal data-analysis approaches, we identified key factors that influenced caregiver mental health over time. First, we identified two groups of caregivers — those whose depressive symptoms were initially high but decreased over time and those whose depressive symptoms remained high over the 1-year follow-up period — and compared patient and caregiver characteristics across groups. Second, using multivariable mixed-effects longitudinal

**Table 2. Mixed-Effects Modeling for Caregiver Outcome Variables.\***

Predictor	Caregiver Outcomes			
	Depressive Symptoms	Psychological Well-Being	Mental Health	Physical Health
	<i>estimated mean difference (95% CI)</i>			
<b>Time since ICU discharge</b>				
7 days to 3 mo	-6.27 (-8.46 to -4.09)†	1.33 (-0.45 to 3.12)	5.07 (2.67 to 7.47)†	-0.11 (-1.73 to 1.51)
3 to 6 mo	-0.59 (-2.05 to 0.86)	0.67 (-0.58 to 1.93)	1.34 (-0.34 to 3.02)	-0.47 (-1.62 to 0.68)
6 to 12 mo	0.57 (-0.94 to 2.08)	-0.08 (-1.45 to 1.28)	-0.12 (-1.78 to 1.55)	-1.09 (-2.24 to 0.06)‡
<b>Caregiver baseline variables</b>				
Age	-1.43 (-2.51 to -0.35)§	1.86 (0.95 to 2.77)†	2.86 (1.59 to 4.13)†	-1.96 (-3.20 to -0.72)§
Caring for a spouse	-2.46 (-4.47 to -0.46)¶	0.64 (-1.02 to 2.31)	0.13 (-2.21 to 2.48)	1.98 (-0.19 to 4.16)‡
Provided care previously	0.71 (-1.17 to 2.58)	-0.55 (-2.12 to 1.01)	-0.64 (-2.81 to 1.53)	-1.12 (-3.19 to 0.95)
Male sex	-1.35 (-3.83 to 1.13)	0.28 (-1.81 to 2.36)	2.93 (0.03 to 5.82)¶	0.14 (-2.57 to 2.85)
Employed	0.29 (-1.68 to 2.27)	-0.09 (-1.74 to 1.56)	-0.02 (-2.32 to 2.28)	-0.60 (-2.80 to 1.61)
<b>Education</b>				
Less than secondary	Reference	Reference	Reference	Reference
Postsecondary	-3.98 (-7.07 to -0.88)¶	2.49 (-0.10 to 5.08)‡	3.14 (-0.50 to 6.78)‡	2.68 (-0.88 to 6.24)
Secondary and some postsecondary	-3.91 (-6.98 to -0.83)¶	1.88 (-0.68 to 4.43)	3.55 (-0.03 to 7.13)‡	2.28 (-1.15 to 5.72)
<b>Caregiver income in Canadian \$</b>				
<\$50,000	Reference	Reference	Reference	Reference
\$50,000–70,000	-3.08 (-5.55 to -0.61)¶	0.08 (-1.95 to 2.11)	1.78 (-1.14 to 4.69)	2.66 (-0.22 to 5.55)‡
>\$70,000	-0.55 (-2.82 to 1.72)	-0.91 (-2.74 to 0.91)	-0.48 (-3.02 to 2.07)	4.59 (2.04 to 7.13)†
<b>Caregiver repeated assessment variables</b>				
Score on Caregiver Assistance Scale	0.35 (-0.46 to 1.16)	-0.08 (-0.79 to 0.62)	0.35 (-0.58 to 1.28)	-0.68 (-1.37 to 0.02)‡
Score on Caregiving Impact Scale	4.69 (3.81 to 5.58)†	-1.70 (-2.47 to -0.93)†	-5.01 (-6.03 to -3.99)†	-1.34 (-2.11 to -0.58)†
Score on MOS Social Support Survey	-2.46 (-3.24 to -1.67)†	1.61 (0.95 to 2.28)†	1.83 (0.91 to 2.74)†	0.37 (-0.35 to 1.09)
Score on Mastery Scale	-4.04 (-4.83 to -3.25)†	2.73 (2.04 to 3.41)†	4.11 (3.20 to 5.02)†	1.08 (0.37 to 1.79)§
Score on Personal Gain Scale	-1.05 (-1.76 to -0.33)§	2.52 (1.89 to 3.14)†	0.98 (0.15 to 1.81)¶	0.09 (-0.57 to 0.74)
No. of supports	-0.34 (-1.37 to 0.68)	-0.03 (-0.92 to 0.85)	-0.06 (-1.25 to 1.13)	0.29 (-0.68 to 1.27)
<b>Patient baseline variables</b>				
Age	0.23 (-0.82 to 1.29)	-0.48 (-1.37 to 0.41)	-0.49 (-1.71 to 0.74)	0.00 (-1.17 to 1.16)
<b>No. of coexisting conditions</b>				
0	Reference	Reference	Reference	Reference
1	0.14 (-2.50 to 2.79)	1.34 (-0.86 to 3.55)	3.26 (0.19 to 6.34)¶	-0.30 (-3.27 to 2.67)
≥2	0.25 (-1.83 to 2.33)	1.19 (-0.56 to 2.93)	0.13 (-2.32 to 2.57)	0.66 (-1.64 to 2.95)
Male sex	1.13 (-1.26 to 3.53)	-0.69 (-2.70 to 1.32)	-0.83 (-3.59 to 1.93)	-1.34 (-3.94 to 1.26)



**Table 2. (Continued.)**

Predictor	Caregiver Outcomes			
	Depressive Symptoms	Psychological Well-Being	Mental Health	Physical Health
	<i>estimated mean difference (95% CI)</i>			
Patient repeated assessment variables				
Score on 6-min walk test**	0.87 (-0.03 to 1.78)‡	-0.75 (-1.50 to 0.00)‡	0.32 (-0.60 to 1.24)	-0.42 (-1.18 to 0.34)
Score on FIM motor subscale††	0.41 (-0.53 to 1.35)	0.30 (-0.56 to 1.15)	0.07 (-1.15 to 1.29)	-0.37 (-1.20 to 0.46)
Score on FIM cognitive subscale‡‡	-0.43 (-1.08 to 0.22)	-0.12 (-0.67 to 0.42)	0.12 (-0.58 to 0.82)	-0.29 (-0.85 to 0.28)

\* Depressive symptoms were assessed according to the score on the CES-D scale; psychological well-being, according to the score on the PANAS Positive Affect Scale; mental health, according to the score on the SF-36 Mental Component Summary; and physical health, according to the score on the SF-36 Physical Component Summary. The values shown are the estimated mean difference in the outcome between the specified time points, for a 1-SD change in a continuous predictor (age), or between the stated level of a categorical variable and the reference level (e.g., caring for a spouse vs. caring for someone other than a spouse). Baseline was 7 days after patient discharge from an intensive care unit (ICU); other assessments were at 3, 6, and 12 months after ICU discharge. CI denotes confidence interval.

† P<0.001.

‡ P<0.01.

§ P<0.05.

¶ P<0.10.

|| Scores on the Personal Gain Scale range from 4 to 16, with higher scores indicating greater discovery of inner strengths as a result of providing care.

\*\* The 6-minute walk test assesses independence in walking, as indicated by the number of meters walked in 6 minutes.

†† Scores on the motor subscale of the Functional Independence Measure (FIM) range from 13 to 91, with higher scores indicating more independence in everyday activities.

‡‡ Scores on the FIM cognitive subscale range from 5 to 35, with higher scores indicating better social functioning and communication.

modeling, we identified factors associated with caregiver outcomes. Together, these analyses suggested that patients' severity of illness, functional abilities (as assessed by the 6-minute walk test and FIM motor subscale), cognitive status (as assessed by the FIM cognitive subscale), and neuropsychological well-being (as assessed by the BDI-II and IES) were not associated with caregiver outcomes. These analyses also suggested that characteristics of the caregiver and caregiving situation were associated with caregiver outcomes during the follow-up year. Caregivers had better health outcomes when they were older, were caring for a spouse, had higher income, and had better social support and sense of control and when caregiving had less of a negative effect on their everyday lives. Our findings are consistent with previous pilot data from Choi et al., who identified two trajectory groups with respect to depressive symptoms<sup>45</sup> and identified caregiver characteristics (younger age, female sex, financial difficulty, and poor health behaviors) but no patient characteristics (diagnosis at admission, ICU length of stay, age, illness severity, and abilities to perform activities and instrumental activities of daily living) that were

associated with poor caregiver outcomes. Additional studies have identified the provision of more assistance per day,<sup>6</sup> the use of paid help, and older patient age<sup>5</sup> as factors related to more depressive symptoms in caregivers. Our study adds to this literature by comprehensively assessing both patient and caregiver characteristics and outcomes and identifying aspects of the caregiving situation that contribute to caregiver health outcomes.

Our study has limitations. First, without a control group or knowledge of caregivers' mental health before the episode of ICU care, we cannot be sure that the high rates of depressive symptoms were a consequence of caregiving. Second, comparison of our cohort with population estimates must be interpreted with caution, because the samples are not matched with respect to important demographic characteristics. Third, the data for the relatively small number of caregivers whose depressive symptoms remained high require validation in a larger sample. Finally, missing data required the use of imputation techniques for patient outcomes included in the multivariable models of caregiver outcomes. In addition, other factors not included in this study

may also influence caregiver outcomes; these include patient variables (e.g., delirium and the patient's ability to reintegrate into the community) and process-of-care variables (e.g., family follow-up and communication with the care team).

This multicenter longitudinal study suggests that critical illness affects long-term outcomes not only in patients but also in their caregivers, increasing the effect of critical illness and societal burden. Our data also suggest that it is not sufficient to support caregivers of only the sickest patients, and family-centered models that cross the care continuum are needed to address caregivers' unique needs for care and support.<sup>46</sup> In addition to established mental health therapies (e.g., cognitive behavioral therapy), interventions that assist caregivers in enhancing their sense of personal mastery, that promote support, and that provide opportunities for them to engage in valued activities (e.g., participation respite) may positively contribute to caregivers' mental health outcomes.

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#### APPENDIX

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